

# Summary of NC Cervical Cancer Coalition Summit

Addendum to CCFNC report, “Cervical cancer prevention in North Carolina: Strengthening health programs and systems”

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## EXECUTIVE SUMMARY

This document is an addendum to the report titled *Cervical Cancer Prevention in North Carolina: Strengthening Health Programs and Systems* (hereinafter referred to as the Report). At the 2013 North Carolina Cervical Cancer Coalition Summit in Raleigh, North Carolina, key stakeholders evaluated ways to improve health programs and systems for cervical cancer prevention. Attendees were more than 80 stakeholders from health departments, private medical practices, national and state organizations, and industry, along with staff from Cervical Cancer-Free North Carolina (CCFNC).

### Key Findings

Attendees agreed that the Northeast and South Central regions of the state have the greatest cervical cancer prevention needs. They noted that, even as intervening in high-need areas is important, we must also continue to focus on areas with larger populations because they have the most cervical cancer cases. Attendees also spoke of substantial gaps in the existing healthcare infrastructure (including limited options for women who are not eligible for screening through the NC Breast and Cervical Cancer Control Program, undocumented immigrants or living in rural areas) and advocated for CME-approved trainings for providers to recommend HPV vaccine. Attendees encouraged providers to emphasize that HPV vaccine prevents several cancers but not to focus on the topic of sex during these discussions.

Of nine recommendations included in the Report, attendees prioritized the following during the closing plenary session at the Summit:

- *Recommendation 2:* Encourage pediatricians, family physicians, nurses, and other healthcare professionals to recommend HPV vaccine.
- *Recommendation 5:* Improve recruitment of women rarely or never screened for cervical cancer with a focus on African American women.

Attendees also conveyed enthusiasm for reducing missed opportunities for screening (Recommendation 6) and increasing awareness of the importance of prevention through HPV vaccination and cervical cancer screening (Recommendation 9).

### Next Steps

CCFNC will conduct follow-up meetings in high-need regions identified in the Report and prioritized by Summit attendees. These regional meetings will happen in early 2014 in the Northeast and South Central regions of North Carolina to facilitate community action plans to implement these recommendations and agreed upon goals and strategies.

### Call to Action

We encourage summit attendees and others to share the Report and this addendum with their colleagues and to attend regional meetings, help develop community action plans, and refine existing practices and programs within their organizations.

## BACKGROUND & PURPOSE

This document is an addendum to the report titled *Cervical Cancer Prevention in North Carolina: Strengthening Health Programs and Systems* (hereinafter referred to as the Report). This addendum summarizes the proceedings of the North Carolina Cervical Cancer Coalition Summit that took place Friday, September 13, 2013. More than 80 stakeholders from health departments, private medical practices, national and state organizations, and industry attended the half-day meeting in Raleigh, North Carolina. Summit attendees highlighted challenges and accomplishments in the fight against cervical cancer and suggested ways to advance cervical cancer prevention and screening efforts. In addition to a presentation describing the burden of cervical cancer in North Carolina, discussions in large groups and breakout sessions considered ways to increase HPV vaccination and cervical cancer screening. Supplementary sections at the end of this addendum report include information on the four breakout sessions:

- High-need, low-resource counties: What's next?
- Overcoming challenges to vaccinations in alternative settings – schools and pharmacies
- Missed opportunities to screen underserved women
- Ways for healthcare clinics and providers to meet cervical cancer prevention goals

## KEY FINDINGS

### Regional Meetings

Summit attendees discussed ideal areas in North Carolina to hold regional gatherings based on cervical cancer prevention need. They agreed that the Northeast and South Central areas were highest priorities. If resources are available, a regional meeting in the west would be useful, as well. Attendees suggested Williamston, Greenville, and Rocky Mount as potential meeting locations in the Northeast region based on centrality, cervical cancer rates, and population density. For the South Central region, one participant suggested the Area Health Education Center (AHEC) in Fayetteville as a possible venue. Haywood and Hendersonville were suggested as potential regional meeting locations in the Western region. Additionally, using a teleconference system at the regional meetings could help increase community participation from those who are unable to attend in person.

### Remembering Why:

#### **Remembering Why: Prevention is Saving One – A Survivor's Remarks**

*At the Summit, Leslie Sinnott shared the inspiring story of her own struggles with cervical cancer. Leslie silently set 4 empty chairs in a row in the front of the room. She then spoke. Leslie told us that 1 in 5 women survive stage IV cervical cancer, the kind of cancer she was diagnosed with in 1997. Leslie was there to speak with us. But the four empty chairs were to remind us of the other four women who did not survive their struggles with cervical cancer – women who could not speak about their struggles with cervical cancer.*

*Leslie attributed her survival to screening, good access to care, and receiving innovative treatments. She talked about the difficulties of treatment and the lingering side effects that she still had from her treatment. These included lymphedema that forces her to constantly wear a compression bandage over it and other lingering symptoms.*

*Cervical cancer is preventable. Ms. Sinnott found the statistics on failures to screen and vaccinate truly upsetting. She noted that, across the state only 16% of girls complete all three doses of HPV vaccine; leaving 84% to play roulette. We can do better.*

Intervening in high-risk areas is important, but we must also focus on areas with larger populations as that is where most cervical cancer cases are.

### **Feedback on Report's Recommendations**

Attendees provided feedback on the Report's nine recommendations and brainstormed additional action steps. They also prioritized two of the recommendations (numbers 2 and 5, noted with a star) based on feasibility and capacity for impact. Plenary discussions and breakout sessions are summarized below, ordered as the topics appear in the Report.

#### ***Recommendation 1: Reduce missed opportunities for HPV vaccination among eligible adolescents.***

Summit attendees noted that many adolescents have infrequent healthcare visits, emphasizing the importance of addressing immunization status during any adolescent interaction with the healthcare system. Specific suggestions included the following:

- Provide HPV vaccine at the same time as Tdap, meningitis, and seasonal flu vaccines.
- Offer HPV vaccine to girls in family planning clinics who are receiving a Depo-Provera shot. The Depo-Provera shot is given every 11-13 weeks; regular patient visits provide an opportunity to complete the 3-dose HPV vaccine series.
- Offer HPV vaccine to Medicaid beneficiaries, including postpartum adolescent mothers.

#### **★ *Recommendation 2: Encourage pediatricians and family practitioners to recommend HPV vaccine.***

Summit attendees urged all primary care providers to recommend HPV vaccine alongside other adolescent vaccines (i.e. Tdap and meningitis). They emphasized that the responsibility to talk about HPV vaccine falls on many people on the health care team, including nurses, physicians' assistants, health educators, school health center staff, and pharmacists. Attendees suggested the following actions:

- Advocate that healthcare professional associations, such as the North Carolina Pediatric Society, the North Carolina Academy of American Family Physicians, and North Carolina Physician Advisory Group, offer tools and CME-approved training on how to recommend HPV vaccine.
- Continue to partner with the North Carolina Academy of Family Physicians to present HPV vaccination information at its annual conference.
- Identify opportunities to partner with the North Carolina Pediatric Society.
- Trainings and presentations for providers should emphasize the following:
  - HPV vaccine is recommended for males as well as females.
  - HPV vaccine is more effective when administered to younger adolescents.
  - HPV vaccine prevents cervical cancer and many other cancers.
  - It is not necessary to focus on topics related to sex when recommending HPV vaccine.

***Recommendation 3: Expand use of alternative settings, including schools, to provide adolescent vaccines (HPV, Tdap and meningitis).*** Attendees discussed the challenges and potential benefits of partnering with schools to increase access to HPV vaccination. School-located provision of adolescent vaccines capitalizes on reaching adolescents in settings where they spend most of their time. Some attendees also recommended involving pharmacies in vaccination efforts, because they naturally reach

individuals of varying socio-demographic backgrounds and increase the convenience and accessibility of obtaining immunizations. In other parts of the U.S., pharmacies administer vaccines to adolescents and also play a role in educating adolescents and parents about HPV vaccine benefits. Expanding HPV vaccination efforts to new settings raises a number of specific challenges that include the following:

- Gaining support from school board members and community stakeholders to deliver HPV vaccine in school-based health centers.
- Balancing the tension between 1) ensuring continuity in care as it is delivered via the medical home model and 2) expanding service points by allowing pharmacies to provide the HPV vaccine. Ideally, a physician-led medical home would administer all three doses of the HPV vaccine; however, this is not always possible. Approving pharmacies to deliver the second and third doses of HPV vaccine may increase vaccination coverage.

While minors may receive HPV vaccine without their parents' consent through laws that specify terms for providing STI prevention services, attendees expressed concern about using this approach as this law is in jeopardy in North Carolina. Using the law's provision for HPV vaccine may draw unnecessary controversy to the law and the vaccine.

***Recommendation 4: Increase funding to establish universal coverage of all ACIP recommended vaccines, including the HPV vaccine, through age 18.*** This is a very important recommendation, but implementing it may be beyond the purview of coalition members, according to Summit attendees.

**★ *Recommendation 5: Improve recruitment of women rarely or never screened for cervical cancer, with a focus on African American women.*** Summit attendees shared their own practices for reaching women who are rarely or never screened and those who may be at elevated risk for cervical cancer, such as African American women, low-income women, Hispanic women, smokers, and undocumented immigrants. Suggested practices to increase screening include the following:

- Consider expanding the focus of the recommendation to include rural and potentially other women at higher risk for cervical cancer.
- Advocate for establishing a BCCCP provider in counties where one does not currently exist.
- Use private insurance and Medicaid claims data to target reminder letter campaigns.
- Use technology, such as electronic health records, to identify patients who have not been screened within the last three years.
- Use mail or outbound automatic dialers to contact patients.

***Recommendation 6: Reduce missed opportunities for cervical cancer screening.*** Summit attendees expressed strong support for this recommendation and suggested the use of information systems and electronic health records to alert providers and patients when a patient is due for screening as a way to reduce missed opportunities for screening.

***Recommendation 7: Encourage adherence to USPSTF recommendations for cervical cancer screening.***

Adoption of guidelines to screen for cervical cancer every three years or less often may free resources to identify and screen women who will benefit most from screening services.

***Recommendation 8: Expand BCCCP Funding.*** Reduction in BCCCP funding, as happened in 2013, threatens the health of women in North Carolina. Coalition members can advocate for restoring funding and for legislation that allows individuals to contribute to BCCCP through a check-box on their state tax returns.

***Recommendation 9: Increase awareness of the importance of adolescent HPV vaccination among parents and of cervical cancer screening among higher-risk women, especially among populations at higher risk for cervical cancer.*** Summit attendees demonstrated enthusiasm for this recommendation and noted that awareness can be increased through the National Cervical Cancer Coalition ([nccc-online.org](http://nccc-online.org)), a support and education group led by survivors or family members of individuals with cervical cancer that has two chapters in North Carolina.

***Additional Comments***

While these recommendations are important steps toward eliminating cervical cancer in North Carolina, other notable challenges exist. For many women, follow-up care for an abnormal Pap test result is unaffordable. North Carolina has a Breast and Cervical Cancer Medicaid (BCCM) program; however, only women enrolled in BCCCP may qualify for BCCM. State funding requires providers to strictly enforce eligibility criteria, leaving many women without coverage. Many underinsured and uninsured women receive screening outside of BCCCP and, therefore, are ineligible for BCCM. Also, undocumented immigrants screened through BCCCP are not eligible for BCCM.

## **NEXT STEPS**

Adoption of the prioritized recommendations, particularly in high-need regions and areas with large populations, has substantial potential to improve cervical cancer prevention. Stakeholders must be committed to exploring ways their organizations can implement these recommendations.

With support from attendees at the summit and other key stakeholders, CCFNC will begin hosting regional meetings in the Northeast and South Central regions of the state in early 2014. The purpose of the regional meetings is detailed below:

- Facilitate collaborative and productive discussions among diverse stakeholders.
- Consider and evaluate the meaningful actions that can be implemented within the existing health system infrastructure.
- Develop specific action plans for how to implement the recommendations.

## BREAKOUT SESSION 1: HIGH-NEED, LOW-RESOURCE COUNTIES: WHAT'S NEXT?

**Facilitator:** Schatzi H. McCarthy, MAPA, MP, Cervical Cancer-Free NC

**Attendees:** 12

### Key Themes

***Pediatricians and family practitioners play a critical role in vaccinating adolescents against HPV.***

Healthcare providers may not know or understand HPV vaccination guidelines, or that HPV vaccine can be offered at the same time as other vaccines. It is important to encourage providers to talk with parents and adolescents about HPV vaccination whenever they discuss other vaccines. Offering HPV vaccine along with other adolescent vaccines (i.e. Tdap and meningitis) and sending out reminder letters to patients and their parents should increase opportunities to administer the HPV vaccine. Healthcare professionals and vaccination campaigns should frame HPV vaccine as a way to prevent cervical cancer rather than a vaccine for genital warts. Presenting HPV vaccination information at the North Carolina Academy of Family Physicians' annual conference may also increase provider awareness (a venue for reaching pediatricians was not identified).

***Schools can play an important role in increasing HPV vaccination.*** Garrett's law requires schools to provide parents with information about adolescent vaccines, but allows schools to do this through any medium they choose (e.g. on the school website). As such, many parents do not find out about recommended vaccines for adolescents (e.g. if parents do not access the school website). While vaccination programs in schools sometimes face challenges, participants noted that Brunswick, Pitt, and Montgomery Counties have successfully offered HPV vaccination clinics at schools.

***Comprehensive sex education may help promote awareness of HPV vaccine among teens.*** Many schools do not offer comprehensive sex education, which attendees identified as a potential barrier to HPV vaccine uptake. However, a representative from Harnett County shared her health department's success in providing semi-annual sex education conferences for adolescent girls. The health department provides information about HPV vaccine to students and parents at these conferences to increase awareness.

***Cost may be a barrier for some women.*** It is important to increase awareness of low- or no-cost screening services available to low-income and uninsured women. Other suggestions included using pop-up reminders in patient registration systems to identify patients for other services such as cervical cancer screening.

***Encourage adherence to US Preventive Services Task Force (USPSTF) recommendations for cervical cancer screening.*** New USPSTF guidelines specify that women should be screened every three years rather than annually. While these guidelines call for fewer screenings and may reduce one source of revenue for some clinics, they may also free up resources to support screening of high-need women.

## BREAKOUT SESSION 2: OVERCOMING CHALLENGES TO VACCINATIONS IN ALTERNATIVE SETTINGS – SCHOOLS AND PHARMACIES

**Discussants:** Greg Griggs, MPA, CAE, NC Academy of Family Physicians; Chris Hoke, JD, Office of Regulatory & Legal Affairs, Div. of Public Health; Macary Marciniak, PharmD, NC Pharmacy Association; John Morrow, MD, MPH, NC Association of Local Health Directors; Regina Smith, MSN, FNP-C, Montgomery County School Health Centers

**Moderator:** Noel T. Brewer, PhD, Cervical Cancer-Free NC and UNC

**Attendees:** ~25

### Key Themes

***Schools and pharmacies can be part of a holistic approach to health and collaborate with each adolescent's healthcare provider, or "medical home".*** The conversation about HPV vaccine is part of a larger conversation about how to deliver comprehensive healthcare for adolescents and young adults. Schools and pharmacies have important roles, but it is essential that including them as points of healthcare delivery does not decrease patient-centered care, diminish coordination of care, or introduce risks associated with fragmented care. There have been a few quality improvement initiatives in primary care settings to address comprehensive screening. As part of these initiatives, physicians screen adolescents to make sure immunizations are up-to-date, but also to assess BMI, risk for depression, and other health-related issues.

***Obtaining consent, resources, and reimbursement are formidable challenges to administering HPV vaccine in schools. Despite such barriers, many have had success in increasing uptake.*** Parental consent for immunizations can be a challenge due to concerns about the vaccine and students withholding consent forms. The resource-intensive nature of school immunization programs is another substantial challenge as is determining the insurance status of students. Despite these challenges, the continued integration of health information systems may diminish these obstacles in the near future. Additionally, middle and high schools are important venues for increasing children's and parents' awareness around the benefits of HPV vaccine.

***Pharmacies are a unique opportunity to increase uptake of HPV vaccination and to make sure adolescents are up-to-date on immunizations.*** Many pharmacies throughout the country already administer vaccines to adolescents and have established mechanisms for tracking inventory and seeking reimbursement. In North Carolina, pharmacies recently gained access to the North Carolina Immunizations Registry and can track vaccinations and identify patients who are in need of immunizations. Moreover, lots of people of various ages, demographics, and socioeconomic backgrounds pass through pharmacies each day. Despite the benefits of convenience, administering HPV vaccine to minors still requires parental consent in most cases, which can be challenging to obtain. Even if pharmacies do not offer HPV vaccine, they can still be important partners in educating adolescents and their parents about its benefits.

### **BREAKOUT SESSION 3: MISSED OPPORTUNITIES TO SCREEN UNDERSERVED WOMEN**

**Discussants:** Laura Benson, RN, MSN, CPHQ, Health Net Federal Services; Debi Nelson, MAEd, RHEd, NC Breast & Cervical Cancer Control Program

**Facilitator:** Jessica DeFrank, PhD, Post-doctoral Fellow, UNC

**Attendees:** ~12

#### **Key Themes**

**Limited resources and staff in health department clinics.** Not all health departments offer BCCCP services. Additionally, gradual budget cuts in BCCCP funding restrict capacity and make it increasingly difficult for organizations to do more with fewer resources. If health department clinics do not provide screening services, it is important that they refer patients to other clinics where those services are provided.

**Reduce missed opportunities for cervical cancer screening.** Among BCCCP providers and health department clinics, lack of funding is a barrier to reducing missed opportunities for cervical cancer screening. Nonetheless, engaging primary care providers and organizations (e.g. North Carolina Obstetrical and Gynecological Society) to reach out to women who are rarely or never screened, and recruiting more IT professionals to train staff in local health departments to upload patient data to the CDC's Immunization Information Systems (IIS) Core Data Elements are some ways to reduce missed screening opportunities.

**Encourage adherence to USPSTF recommendations.** It is important to have updated training materials, including new BCCCP and Pap test manuals that reflect new USPSTF recommendations for cervical cancer screening.

**Encourage BCCCP to optimize their use of their budget.** BCCCP must continue to engage partners and be creative in stretching funds through training and technical assistance.

**Implement strategies used by Health Net, an organization that provides managed care support for the TRICARE North Region, to increase cervical cancer screening rates.** Checking a patient's chart thoroughly and walking the patient to the front desk to make sure she schedules an appointment were some of the methods used by healthcare providers with high performance screening ratings. Health Net providers identified women overdue for an appointment through claims data and sent them letters, including second and third notices, with easy-to-understand personal narratives written at the sixth-grade reading level. They also used technology, including fax and email blasts to providers and auto-telephone dialing patients and providers, to promote cervical cancer screening.

## **BREAKOUT SESSION 4: WAYS FOR HEALTHCARE CLINICS AND PROVIDERS TO MEET CERVICAL CANCER PREVENTION GOALS**

**Discussants:** Holly Biola, MD, Community Care of North Carolina; Shannon Dowler, MD, NC Academy of Family Physicians; Jean C. Smith, MD, NC Pediatric Society

**Facilitator:** Melissa Gilkey, PhD, Post-doctoral Fellow, UNC

**Attendees:** 16

### **Key Themes**

#### ***Train physicians and healthcare providers on how to discuss HPV vaccine and cervical cancer prevention with patients.***

Education about prevention is an important part of improving screening and vaccination. Physicians, nurses, and health educators need appropriate training to inform patients and parents about the benefits of HPV vaccination. These trainings do not need to be entirely focused on cervical cancer prevention, but should address how to integrate the discussion of HPV vaccine into the conversation about general health practices. Professional associations, such as the American Academy for Family Physicians, currently distribute prepared presentations on HPV vaccine; these presentations teach providers how to discuss the vaccine with patients and parents.

#### ***Create opportunities for patient education and make it the shared responsibility of physicians, nurses, and health educators.***

Physicians, nurses, and other healthcare providers already feel overburdened; emphasizing a shared responsibility for patient education can address this challenge. Additionally, opportunities exist to educate individuals outside of the exam room; health departments, school health clinics, and pharmacies are all appropriate settings.

#### ***Use existing information systems to identify individuals who have not been screened recently or who are not up-to-date on HPV vaccine.***

Integrated information systems have the capacity to use claims data to easily generate reports of individuals who are overdue for Pap tests or not up-to-date with HPV vaccine. Although claims data are imperfect and do not include women who have never entered the health system, they are a useful tool for increasing recruitment of rarely or never screened women. Community Care of North Carolina's Quality Measures and Feedback program collects chart audited data at the practice level that can be aggregated to the regional and state levels, as well. This information is available to providers.

#### ***Go beyond the routine of medicine.***

Healthcare for children and adolescents revolves around immunization sequences and school requirements for physical examinations. While this approach promotes regular annual physician visits among healthy children, a conversation about vaccines can occur at any type of appointment; doing so may help reduce missed opportunities.

#### ***Position HPV vaccine and regular screening in the context of comprehensive healthcare.***

HPV vaccine should be bundled with other adolescent vaccines (i.e. Tdap and meningitis). Though some physicians may be reluctant to talk about HPV because they are reluctant to discuss sex or sexually transmitted infections, training for how to discuss the vaccine as cervical cancer prevention and normalizing it by pairing it with other accepted vaccines can help physicians overcome this issue.